



NATIONAL
QUALITY FORUM

Patient-Centered Measurement: Innovation Challenge Series

Learning Collaborative 2018 Webinar

Tuesday, January 23, 2018

WELCOME



Laura Batz Townsend, BA
President & Co-Founder

[Louise H. Batz Patient Safety Foundation](#)

2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

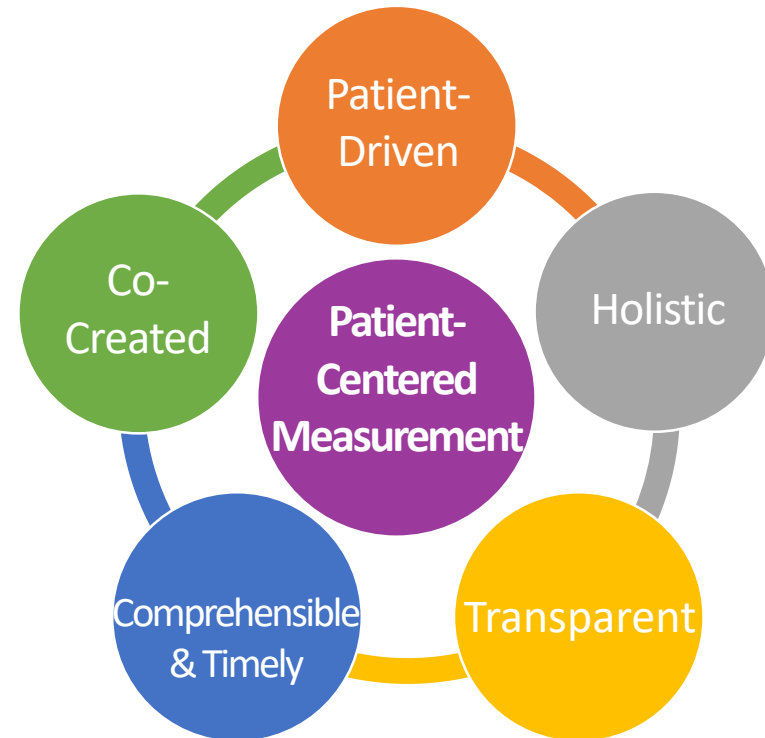
Background

- Patient-centered measurement drives patient-centered care
- Substantial gaps exist in meaningful, patient-centered measures
- We need real-world experiences, grounded by a sound framework

2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

Objectives

- Share [Principles for Making Health Care Measurement Patient-Centered](#)
- Identify innovative practices
- Promote solutions to barriers
- Accelerate improvement



Graphic courtesy of [American Institutes for Research](#).

2017 Innovation Challenge

Details

- Novel solutions to patient-centered measurement challenge
- Incorporate 1+ [Principles for Making Health Care Measurement Patient-Centered](#) across measurement lifecycle
- Emphasis on patient/caregiver priorities and engagement
- Existing or theoretical solutions

2017 Innovation Challenge

Evaluation Criteria

- Significant contribution to patient-centered measurement
- Broadly applicable
- Novel approach
- Demonstrated success
- Replicable

2017 Innovation Challenge

Submissions

- 32 submissions received Oct 16 – Nov 15, 2017
- 5 submissions selected to receive a cash award and a national platform to share ideas
 - *Webinar 1: January 23*
 - *Webinar 2: February 8*
 - *Webinar 3: March 1*
- All submissions become part of NQF Learning Collaborative

2017 Innovation Challenge

Winning Submissions

- **Colleen A. McHorney, PhD, Evidera and Dayo Jagun, MBBS, MPH, Genentech**

Share ongoing work where patients and caregivers have a central role in conceptualizing oncology measures that address patients' concerns, values and preferences

2017 Innovation Challenge

Winning Submissions

- **Saraswathi Vedam, RM, FACNM, SciD, MSFHR Health Professional Investigator, Birth Place Lab, University of British Columbia**
Describes the development and validation of patient-designed measures of autonomy and respect, as well as patient-reported items that capture mistreatment in maternity care
- **Katharina Kovacs Burns, MSc, MHSA, PhD, Alberta Health Services**
Explores a strategy to engage patient and family advisors in gathering and analyzing patient experience data in real-time

2017 Innovation Challenge

Winning Submissions

- **Sameer Saini, MD, MS, VA Ann Arbor Center for Clinical Management Research and University of Michigan Institute for Healthcare Policy and Innovation**

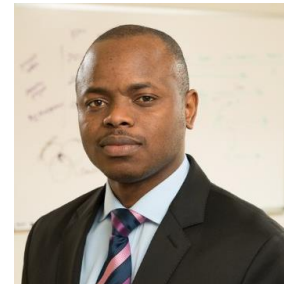
Outlines measures of colorectal cancer screening that incorporate individual screening benefit and patient preferences

- **Matthew Pickering, PharmD, RPh, Pharmacy Quality Alliance and Eleanor Perfetto, PhD, MS, National Health Council**

Propose a rubric to assess the patient-centeredness of measure development and implementation

Today's Presenters

- Colleen A. McHorney, PhD, Senior Research Leader, Patient-Centered Research, [Evidera](#)
- Dayo Jagun, MBBS, MPH, Medical Director, Quality of Care, Evidence for Access Medical Unit, [Genentech](#)



Patient-Driven Quality Indicators in Cancer

A New Approach to Quality Measure Development

Presenters

- Colleen A. McHorney, PhD
 - Senior Research Leader, Patient-Centered Research, Evidera
- Dayo Jagun, MBBS, MPH
 - Medical Director, Quality of Care, Genentech

Acknowledgements

Evidera

- Sonja Stringer, MPH
- Rebecca (Becks) Speck, PhD, MPH
- Huda Shalhoub, PhD
- Andrea Schulz, MA
- Sally Mannix, BA
- Brooke Currie, MPH
- Hayley Syrad, PhD
- Owen Cooper, MSc

Genentech

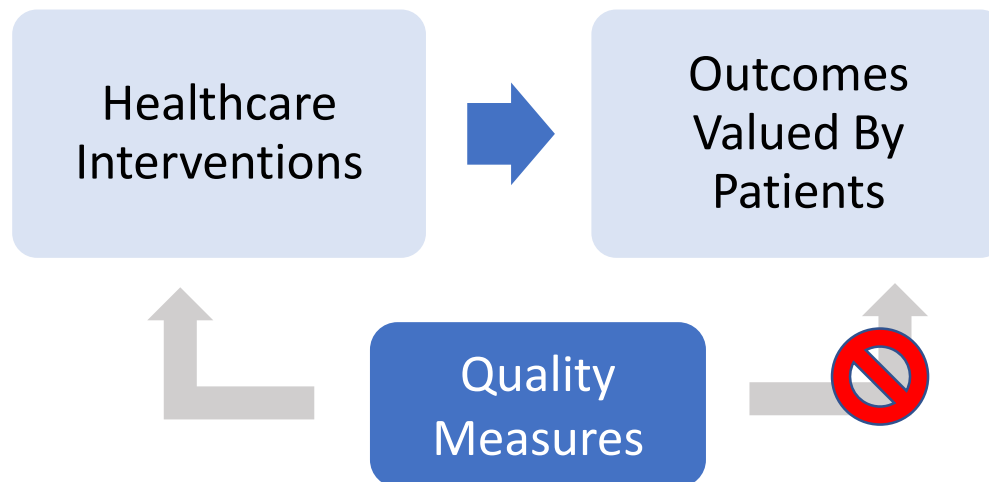
- Anthony Masaquel, MPH, PhD
- Esprit Ma, MPH
- Sarika Ogale
- Sarah Donelson, MA

Outline

- Introductions
- Key points:
 - What is the patient-centered measurement challenge?
 - What do we expect to accomplish?
 - What effort is required?
 - How are patients and caregivers engaged to address their priorities?
 - What lessons did we learn?
- What do we plan to do with our results?
- Questions and discussion

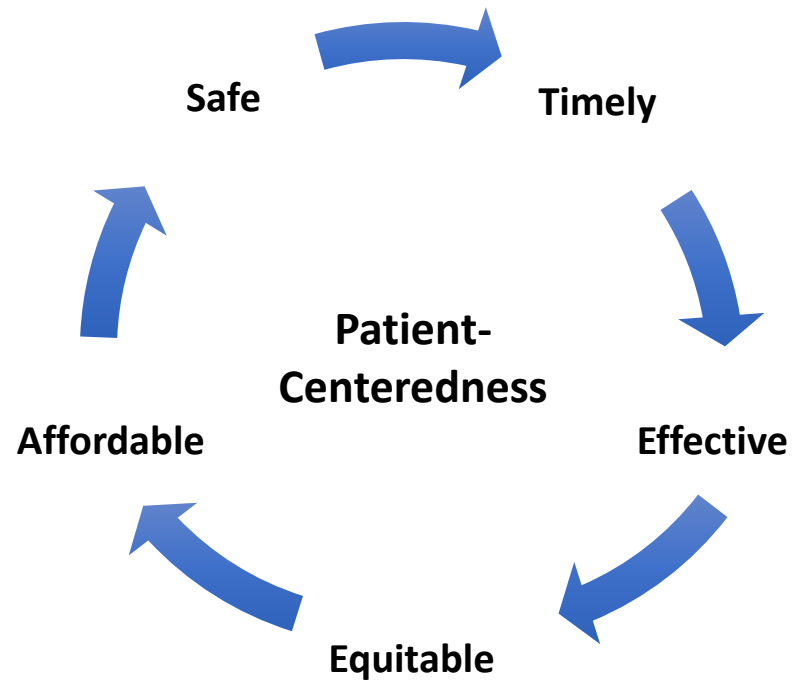
What is the patient-centered measurement challenge?

- There is a definitive lack of:
 - Patients and caregivers playing a *central* role in the conceptualization of quality measures
 - Measure sets that comprehensively address patients' *concerns, values, and preferences*
- As such, there is poor linkage between healthcare interventions, outcomes valued by patients, and quality measures intended assess these outcomes.



What motivated us to address this challenge?

- Increasing focus on patient-centeredness in research, health policy, and clinical practice
- Increasing incentives to receive and deliver value-based healthcare



Volume-Based (FFS)

Paying for
Every Unit of
Care
Delivered
Regardless of
its Value

Value-Based

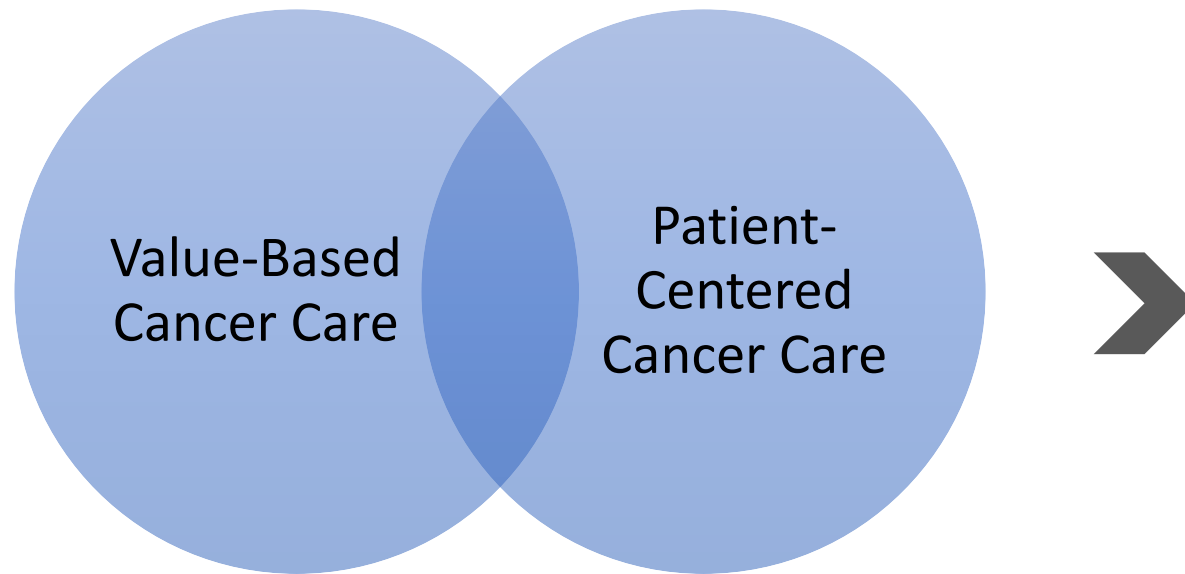
Paying for High-
Value Care
Delivered

FFS = fee for service

“Value” in healthcare has been defined as the quality of care achieved (numerator) divided by the cost of care (denominator). Porter ME. What is value in health care? *N Engl J Med* 2010;363(26):2477–81.

What do we expect to accomplish?

- We aspire to identify aspects of oncology care that are important to patients and caregivers and, therefore, should be assessed as quality measures across the cancer patient care pathway.
- We aim to identify the intersection between value-based care and patient-centered care by defining value from the patient perspective.



Sets of quality-of-care indicators that:

- Represent patients' values and preferences
- Enable the definition of high-value cancer care from the patient perspective

Less than 7% of endorsed quality measures for cancer care assess patients' perceptions or experiences of their care (Spinks 2011; Sohn 2016)

Quality indicators in cancer

Current quality indicator for outcomes

- Surgical mortality
- Emergency-room visits
- Hospital readmission
- Length of stay

- Administrative data – narrow measures of convenience
- Incomplete assessment of quality

Patient-centered quality indicator for outcomes

- Health-related quality of life
- Symptom management
- Patient experience

- Requires patient surveys
- Integration into EHR



Do traditional measures actually improve care, and do they matter most to patients and their families?



Value should be defined around the patient – *what matters most to patients* in terms of quality

HER = electronic health record

For illustration only; based on a quality measure under development by the National Committee for Quality Assurance. Available here:

http://www.ncqa.org/Portals/0/PublicComment/MIF_PRO_Public_Comment.pdf?ver=2016-10-04-144602-713

Quality indicator: What could it look like?

Indicator

- Patients receiving outpatient chemotherapy treatment should be assessed using a validated multi-symptom assessment tool at every chemotherapy administration during the treatment episode



Measure

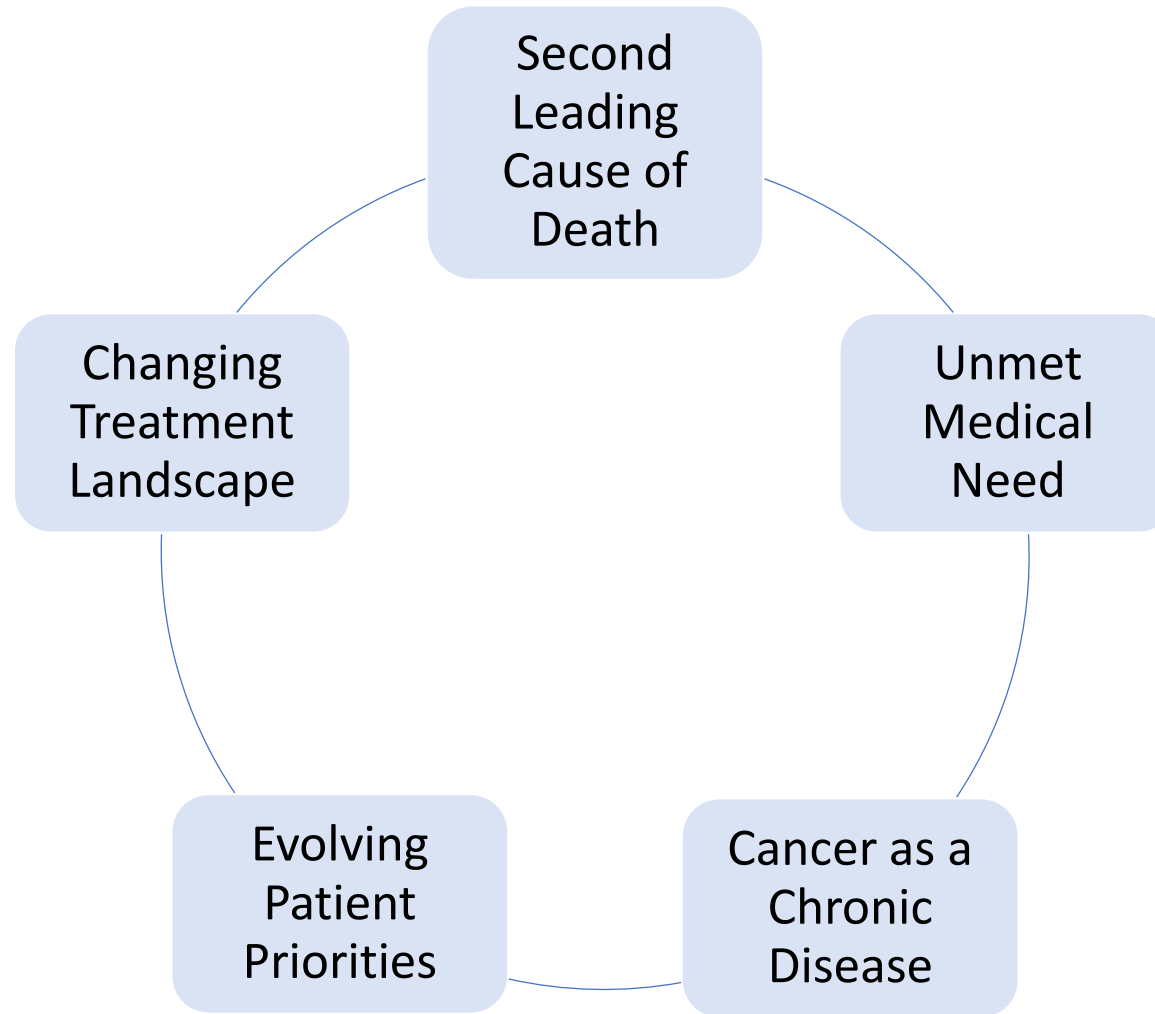
- **Denominator:** Patients aged 18 years and older before the start of the measurement period with a diagnosis of any cancer and at least two outpatient encounters for chemotherapy treatment at the reporting facility during the measurement period
- **Numerator:** Number of patients who completed a multi-symptom assessment tool (MDASI, PRO-CTCAE, EORTC QLQ-C30, or FACT) at every chemotherapy administration during the treatment period

EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30;
FACT = Functional Assessment of Cancer Therapy; MDASI = MD Anderson Symptom Inventory; PRO-CTCAE = Patient-reported Outcome Common Terminology Criteria for Adverse Events

For illustration only; based on a quality measure under development by the National Committee for Quality Assurance. Available here:

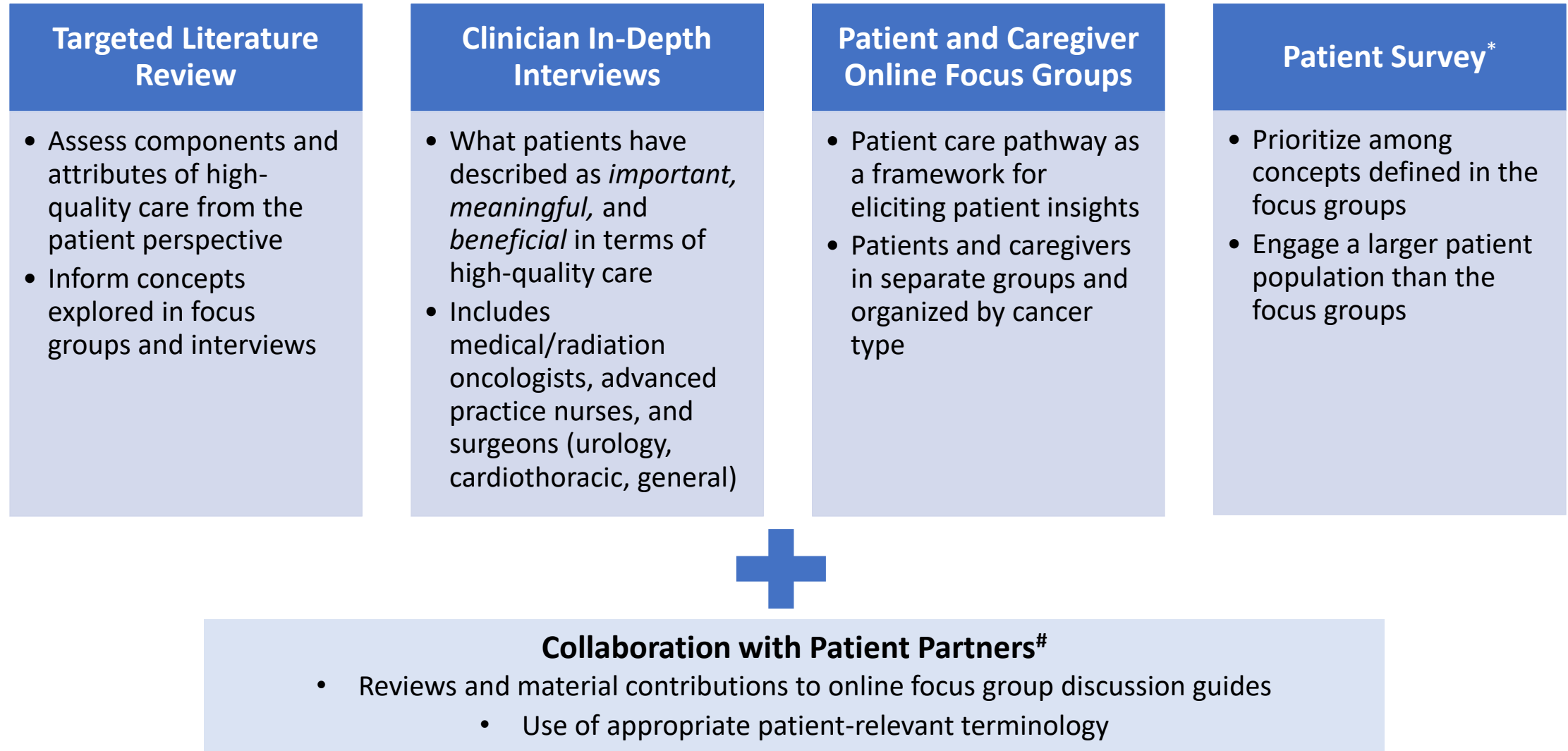
http://www.ncqa.org/Portals/0/PublicComment/MIF_PRO_Public_Comment.pdf?ver=2016-10-04-144602-713

Why focus on cancer?



Note: We selected a mix of solid and liquid tumor types as an initial set: Colorectal cancer (CRC), non-Hodgkin's lymphoma (NHL), chronic lymphocytic leukemia (CLL), non-small cell lung cancer (NSCLC), bladder cancer (BdCA), and renal cell carcinoma (RCC)

Methods: Patient and caregiver priorities are addressed In multiple ways



*Patient survey will be conducted for only NSCLC, RCC, and BdCA

Patients partners were engaged for CRC, NHL, and CLL only

Effort required: Summary of the numbers

Targeted Literature Reviews	Clinician In-Depth Interviews	Patient and Caregiver Online Focus Groups	Patient Survey*
<ul style="list-style-type: none">• 287 articles met inclusion criteria• 57 included in review	<ul style="list-style-type: none">• 8 MedOncs• 4 HemOncs• 7 RadOncs• 7 APN• 3 Urologists• 3 Oncology surgeons• 3 Thoracic surgeons• 2 General surgeons	<ul style="list-style-type: none">• 86 patients• 28 caregivers	<ul style="list-style-type: none">• 135 patients and caregivers

APN = advanced practice nurse; HemOnc = hematology oncologist; MedOnc = medical oncologist; RadOnc = radiation oncologist

*Patient survey will be conducted for only Non-small Cell Lung Cancer, Renal Cell Carcinoma, and Bladder Cancer

Patients partners were engaged for CRC, NHL, and CLL only

Effort required: Literature review

Targeted Literature Reviews

- Identify *patient-centered* attributes of the process and outcomes of cancer treatment from the peer-reviewed literature
- What are the components and attributes of cancer care quality from a *patient-centered point of view*?
- How do patients prioritize different attributes of the quality of cancer care?
- The targeted literature review provided valuable insights for the development of the clinician and patient/caregiver interview guides.

Effort required: Clinician interviews

Clinician Interviews

- 37 clinician interviews conducted
- All clinicians were currently involved in some type of value-based payments
- Have your patients ever articulated to you comments about the quality of their cancer care?
- What have your patients told to you *is important and beneficial to them* in terms of quality of cancer care?
- What areas of concerns or problematic events have your patients mentioned to you about the quality of their cancer care?
- What areas of praise or admiration have your patients mentioned about the quality of their cancer care?
- Clinicians were asked to provide two perspectives: (1) what represents the quality of care of each care pathway from the clinicians perspective and (2) what represents the quality of care of each care pathway from the patient perspective

Clinician responses were coded into 17 discrete quality-of-care themes

Quality-of-Care Themes		
Symptom/side-effect management	Cost-finances/insurance	Psychosocial/emotional well-being
Clinical outcome	Physician communication	Patient expectations
Timeliness of care	Interpersonal care/style	Family support
Coordination of care	Quality of life	Physical well-being
Technical quality (standard of care)	Access/logistics	Patient involvement
Patient knowledge	Patient-centered care	

Effort required: Online focus groups

Patient and Caregiver Online Focus Groups: Approach

- Used focus groups to discover attributes of oncology care that are important and meaningful to cancer patients and their caregivers
- Group interaction tends to produce insights that do not surface in individual interviews
- Stratified groups by gender
- Caregiver focus groups were conducted separately from the patient groups
- Patient focus groups were held separately for each cancer diagnosis
- Conducted online focus groups because they offer: (1) cost efficiency; (2) potential to reach a broad geographic scope; and (3) a convenient and comfortable way of participating among cancer survivors
- Online focus groups were synchronous (in real time with “Brady-Bunch” like viewing of participants)

Effort required: Online focus groups

Patient and Caregiver Online Focus Group: Key Questions

- Reflecting on your whole pathway—from start to finish (or from start to now)—what does “quality of care” mean to you personally? It is not limited to what you actually experienced. It can also be ideal quality of care that you wished you had received
- Reflecting on your whole pathway, how would you have changed your care you received (the health care system, your health care providers, and your health care experiences)?
- For each pathway phase, we asked: (1) how would you have liked to change the health care you received if you were able to do so? and (2) what *care, support, resources, or information* did you feel you needed but was not provided to you?

Patient and caregiver responses were coded into 21 discrete quality-of-care themes

Quality-of-Care Themes		
Information giving/provide communication	Community health and social services	Physical comfort
Humaneness/art of care	Access to care	Patient values, preferences, choice, autonomy
Technical competence	Patient-centeredness/individualism	Costs/finances/insurance
Timeliness of care	Treatment expectations	Physical facilities
Psychosocial/emotional support	Coordination of care	Treatment convenience
Symptom/side-effect management	Enough time with clinician	Bureaucratism
Caregivers/family/friends	Pain management	Help with self-management/health promotion

Effort required: Patient and caregiver survey

Patient and Caregiver Survey

- Will cross-validate qualitative findings with survey research
- Survey development in process
- Survey will likely include forced rankings and importance ratings of quality-of-care attributes
- May include some quality-of-care vignettes for forced rankings and importance ratings
- Will likely focus on the entire cancer-care pathway overall instead of being pathway specific

Limitations

Selection Bias

Survivorship/
Minimization Bias

Only Six Cancers

Few Caregivers of
Patients Who Died

Pediatric Population
Largely Excluded

Effort required: Recruiting our patient partners

People

- Genentech and Evidera identified and worked with patient-advocacy organizations
 - Colon Cancer Alliance and Fight Colorectal Cancer
 - Lymphoma Research Foundation
 - CLL Society Inc.
- Each advocacy organization supported our recruitment of patient partners and recommended several candidates

Funding

- Patient partners were compensated for their time

Time

- Contracting with the patient partners took up to five weeks

Effort required: Onboarding our patient partners

- **Genentech and Evidera had a 30-minute teleconference with each patient partner for the following purposes:**
 - Genentech's motivation for initiating the collaboration
 - Evidera's methodologies for study execution
 - The partner's personal pathway through cancer care
- **Patient partners were tasked to review and comment on the following:**
 - Focus-group discussion guide
 - Qualitative report
 - Draft manuscript
- **One patient partner took part in a mock online focus group so we could test the online platform and time the length of the discussion**
- **One patient partner completed the focus group discussion questions in writing**

Lessons learned from our patient partners: Words matter

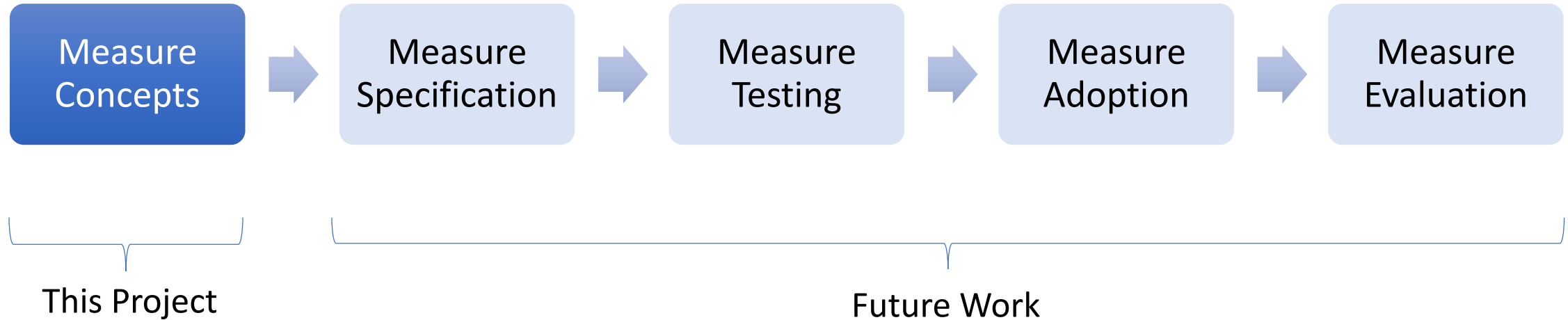
- Do not use the phrase “patient journey”



“For me and many of my friends/group support acquaintances, it is difficult to call NHL a journey since it is a lifelong condition (at least for now). When I opened the document it refers to it as a pathway. I really appreciate that terminology much better as it is indicative of something we are experiencing and going through, but more than likely not just once. A journey is an adventure and something pleasant, I want to be positive about my diagnosis, but that's just too much for us who have been coping with it for longer than the initial diagnosis and first couple of treatments. Anyway, so great job finding a more appropriate phrase to use during the process!”

- It is acceptable to use the word “survivorship” (as in survivorship plan)—that word should not be upsetting or off-putting to cancer survivors
- Two partners commented that the term “palliative” care can be misunderstood by individuals. This term triggers “end of life/hospice” for some cancer patients. They were not sure everyone understands the meaning
- Partners did not like the term “redesign” (“as in how would you redesign your cancer care if you had the power to do so”). They preferred “customize” or simply “change the care you received”

Lessons learned: Factors for future adoption



Successful development and adoption of patient-driven, cancer-quality measures will require:

- A deeper analysis of the data to prioritize among measure concepts for further use
- Accounting for patient-to-patient variation in clinical, demographic, and socioeconomic characteristics
- Direct and ongoing patient involvement at every step
- Cross-disciplinary collaboration across clinicians, researchers, payers, health systems, and policymakers

Challenges to patient-centered quality-of-care assessment

Evidence-based

Disease-specific vs.
cross cutting

Accepted as valid and
relevant by
stakeholders (provider
and payer buy-in)

Feasible to implement
(workflow integration)

Interpretable and
actionable

Risk adjustment

Patient-centered care is recognized as a important quality aim. But, when will it be measured and monitored as such?

Next steps

Dissemination of Our Findings

- Peer-reviewed publication
- Executive exchanges

Stakeholder Engagement

- Patient groups, providers, and payers
- Discuss implications and use cases for our results

Questions and Discussion

Audience Question & Answer

Wrap Up & Announcements

Acknowledgements

Special thanks to the 2017 Innovation Challenge Reviewers:

David Andrews, Patient Advisor

Pam Dardess, MPH, VP for Strategic Initiatives and Operations, Institute for Patient- and Family-Centered Care

Hala Durrah, MTA, Patient Family Engagement Consultant, Speaker & Advocate

Eileen Esposito, DNP, RN-BC, CPHQ, Vice President for Ambulatory Care, Catholic Health Services of Long Island

Stephen Flaherty, MPH, Director of Standardization and Benchmarking, International Consortium for Health Outcomes Measurement

Chris Gibbons, PhD, National Institute for Health Research Fellow, Cambridge Centre for Health Services Research

Wendy Prins, MPH, MPT, Senior Advisor, National Quality Forum

Ellen Schultz, MS, Senior Researcher, American Institutes for Research

Tracy Spinks, BBA, Senior Director, Quality Innovation, National Quality Forum

Laura Batz Townsend, BA, President & Co-Founder, Louise H. Batz Patient Safety Foundation

2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

Focus on Patient-Centered Healthcare Measurement

- Register to learn from other 2017 Innovation Challenge winners...
 - [February 8, 2018 at 1pm ET](#)
 - [March 1, 2018 at 1pm ET](#)
- Register for [NQF's Annual Conference](#), March 12-13 in Washington, DC, for a special session, **NQF Measure Incubator™—Past, Present, and Future**
- To learn more, please contact NQF at incubator@qualityforum.org
- Share your ideas with us [#ptvoice](#) [#ptcenteredmeasures](#)

THANK YOU